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Non-Traditional Surrogate Decision Makers for Hospitalized Older Adults

Amber R. Comer, PhD, JD[1,2], **James E. Slaven, MS**[3], **Annie Montz**[4], **Emily Burke**[4], **Lev Inger**[4], and **Alexia Torke, MD, MS**[2,4,5,6]

[1]Indiana University School of Health and Rehabilitation Sciences

[2]Regenstrief Institute, Inc

[3]Indiana University (IU) Department of Biostatistics

[4]Indiana University Center for Aging Research

[5]IU Division of General Internal Medicine and Geriatrics

[6]Fairbanks Center for Medical Ethics

Abstract

Background—Without advanced preparation of legal documents, state law determines who may serve as a surrogate decision maker for patients in hospitals.

Objectives—To examine the relationship characteristics associated with traditional versus non-traditional healthcare surrogates who are making medical decisions for patients in hospitals.

Research Design—Secondary analysis of a **baseline cross-sectional survey of a larger** prospective observational study.

Subjects—364 patient/ surrogate dyads consisting of patients age 65 years and older admitted to the medical or medical ICU services who lacked decision making capacity based on a physician assessment and also had a surrogate available.

Results—This study of surrogate decision makers for hospitalized older adults found that the relationships of non-traditional surrogates such as, nieces, nephews, and friends serving in the surrogate role is nearly identical to those of traditional, first degree relatives serving as a surrogate. Over two-thirds (71.2%) of non-traditional surrogates saw the patient in person at least weekly compared to 80.8% of legal surrogates (p-value .9023). Almost all traditional and non-traditional surrogates discussed the patient's medical preferences with the patient (96.9% of legal surrogates and 89.2% of non-traditional surrogates; p=0.0510).

Conclusion—This study shows that both traditional and non-traditional surrogates, who are a patient's primary care giver have similar relationships with patients. The findings of this study suggest that **requiring family members such as grandchildren** to take the extra step of formal appointment through a legal channel may not be necessary to protect patients. Therefore, broader

Corresponding Author: Amber R. Comer, PhD, JD, Indiana University School of Health and Rehabilitation Sciences, 1140 W Michigan Street, Coleman Hall 120, Indianapolis, IN 46202, comer@iu.edu, Fax: (317) 274-4723, Telephone: (317) 274-1026.

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state laws expanding the list of surrogates authorized by state statute to include **more** non-traditional surrogates may be necessary.

INTRODUCTION

Almost half of all hospitalized older adults require a surrogate to help make their health care decisions (1–2). There is consensus that the most ethically appropriate surrogate is the person who is best able to convey the patient's desires, needs, and goals (1, 3–5). Traditionally, immediate family members, including spouses, parents, adult children and siblings, have filled the role of the surrogate decision maker because they are assumed to hold the strongest concern for protecting the patient's autonomy and to have the best insight about the care the patient would want (1, 3–4, 6–8). Although immediate family members have customarily been granted unequivocal surrogate decision making authority under the law, the concept of what constitutes a family has evolved over time (9–10). As a result, many non-traditional, but ethically qualified surrogates, such as long-term unmarried partners and grandchildren, are not legally allowed to serve as surrogate decision makers in some states without forward-thinking appointment by the patient through a legal document such as a health care power of attorney or health care representative form or retrospective appointment through a court established guardianship (11).

As it has traditionally been assumed that immediate family members are the most appropriate surrogate, there is a rich history of literature surrounding the relationship characteristics between immediate family members, such as spouses, parents, adult children and siblings, and surrogates (1, 3-4, 12). On the other end of the spectrum, there is a large body of literature describing situations where the patient does not have any person to serve as a surrogate (13–17). However, many patients have relationships which place them in the middle of the spectrum – they have a close surrogate such as a granddaughter or unmarried partner, but this "non-traditional" surrogate is not legally recognized without an existing legal document, such as a health care power of attorney or health care representative form. Little is known about the relationship characteristics between this group of non-traditional surrogates and patients.

To address this knowledge gap, we conducted a study to examine the relationship characteristics associated with older adult patients who have "traditional surrogates", defined as an immediate family member including a spouse, adult child, parent, or sibling, and those surrogates who were close to the patient, but not immediate family, "non-traditional surrogates". This study will inform physicians, hospitals, and state lawmakers about any meaningful differences in the relationship characteristics between traditional versus non-traditional surrogates that would affect non-traditional persons' ability to serve as a high quality surrogate.

METHODS

This is a secondary analysis of a **baseline cross-sectional survey of a larger** prospective observational study **which validated a survey of surrogate-clinician communication in hospitals** (18). **All data in this analysis are from the baseline interview**. Patient-surrogate

dyads consisting of patients age 65 years and older admitted to the medical or medical ICU services in three participating hospitals from a Midwestern metropolitan area were enrolled. Eligible patients lacked the capacity to make medical decisions based on the judgment of their primary hospital physician and had an available surrogate. The surrogates must have faced at least one of three major types of decisions (life sustaining therapy, procedures and surgeries, or discharge placement) during the hospital stay of interest. **Data was self-reported by** surrogates **who** were interviewed at enrollment, (between three and ten days of hospitalization) as well as at two follow-up time points: 6–8 weeks and 6 months.

We asked the primary hospital physician to identify the person who was working with the physician to make medical decisions for the patient. We then determined the traditional surrogates, which includes someone who is identified as a spouse, parent, adult sibling or child in order to understand if there are important patient-surrogate relationship distinctions between traditional and non-traditional surrogates making medical decisions. The IUPUI Institutional Review Board provided approval for this study.

In addition to demographic information, surrogates were given categorical options to respond to questions about the frequency of communication with the patient prior to hospital admission (never, less than once a year, yearly, monthly, weekly, more than weekly, refused to answer) distance the surrogate travels to be with the patient (miles from hospital), and whether the surrogate had discussed medical decision making with the patient (yes or no). Additionally, surrogates were asked their relationship to the patient and both their income and the patient's income (under $24,999, $25,000 – $49,000, $50,000 – $74,999, $75,000 – $99,999, over $100,000, not determined, refused to answer, don't know).

General descriptive statistics are given as frequencies (percentages) for categorical variables and as mean (standard deviation) or median (range) for continuous variables. Analyses to compare outcomes by surrogate status were performed using Chi-Square tests for categorical outcomes and using Student's t-test for continuous outcomes. All analytic assumptions were verified. If assumptions were violated, data transformations were performed, with non-parametric tests being used where necessary. **As the analysis were cross-sectional, all subjects with missing data were excluded from the analysis**. All analyses were performed using SAS v9.4 (SAS Institute, Cary, NC).

RESULTS

Out of N = 799 eligible patient-surrogate dyads, N = 369 (46.2%) were enrolled, with a final sample size of N = 364 (45.6%) dyads finishing the study (five withdrawals). A total of N = 364 patient surrogates were surveyed during the study period. The patients had a mean age of 81.9, 61.5% were women, 69.0% white, and 27.8% African American. Surrogates' mean age was 58.3; 70.9% were women. Surrogate race was nearly identical to the patients' race. Income varied from under $24,999 (19.8%) to over $100,000 (12.4%). Almost 15% of persons serving as the patient's surrogate were considered non-traditional surrogates (Table 1). Of these non-traditional surrogates, nieces and nephews were most likely to serve as a patient surrogate (5%), followed by step-children (2%) (Table 1).

Overall, traditional surrogates were marginally more likely to be older (*p*-value .0590) and significantly better educated (*p*-value .0474) than non-traditional surrogates, although these differences were relatively small (3.2 years of age and less than 1 year of education) (Table 2). Additionally, patients with traditional surrogates were more likely to be married than patients with non-traditional surrogates (*p*-value <0.0001) (Table 2). Gender, race, surrogate marital status, and income were not found to be statistically significant **associated with** whether a patient had a traditional or non-traditional surrogate (Table 2).

Over two-thirds (71.2%) of non-traditional surrogates making medical decisions for patients provided the patient with help at least once per week, which was comparable to 80.8% of non-traditional surrogates, Chi-Square test, p=0.2624. No significant difference in frequency of in person communication with the patient was found between traditional and non-traditional surrogates (p=0.9023) (Table 3). In general, the distances traveled to both the hospital and to the patient's residence were similar between traditional and non-traditional surrogates (the differences are very slight and not statistically significantly different, with the medians being the same and interquartile ranges being similar) (Table 3). Almost all traditional and non-traditional surrogates indicated that they had discussed the patient's medical preferences with the patient (96.9% of traditional surrogates and 89.2% of non-traditional surrogates; *p=0.0510*).

DISCUSSION

This study of surrogate decision makers for hospitalized older adults found that the relationships of non-traditional **family** surrogates such as, nieces, and nephews serving in the surrogate role is nearly identical to those of traditional, first degree relatives serving as surrogate. These findings suggest that **non-immediate family members** should be allowed to serve as patient surrogates **when immediate family members** are not available. Given that half of all older adults require a surrogate to assist with medical decisions, and that many older adults rely on non-traditional surrogates, state law makers, hospitals, and physicians should consider the value of expanding **which relatives** are allowed to act as surrogates without legal appointment.

Based on this study's findings, it is important to reevaluate surrogate decision making statutes for five reasons. First, surrogate laws are state specific and many exclude non-traditional surrogates such as grandparents, grandchildren, nieces, and nephews (19). Second, ethically appropriate surrogates who know the patient's desires should be able to make medical decisions for patients (1). Third, the overwhelming majority of patients fail to appoint a legal surrogate and as such, rely on state surrogate decision making laws to determine who may make their medical decisions (20–23). Fourth, when a patient fails to appoint a legal surrogate prior to needing one, all non-traditional surrogates must petition the court to establish a healthcare Guardianship in order to make medical decisions for their loved one (24–25). Establishing a Guardianship is both costly and time consuming (24–25). Lastly, laws which limit surrogates to only traditional persons place physicians in the position where they have to choose between allowing the non-traditional surrogate to make medical decisions even though it is against the law, or the physician must send the surrogate to court to obtain a Guardianship (26).

Studies have found that less than 20% of hospitalized patients provide legal documentation of their health care surrogate (19–22). Legal documentation is low despite concerted efforts at both the state and federal levels, such as the Patient Self Determination Act (PSDA), which requires health care providers to ask if a patient has an advanced directive and if not, whether they would like assistance completing one (27). As the majority of patients do not take the initiative to legally appoint surrogates, state laws determine who is allowed to serve as a surrogate. When state laws fail to include ethically appropriate surrogates, such as grandchildren, the surrogates, physicians, and patients are left to deal with the consequences.

This study has several limitations which require further investigation. First, this study was conducted at three medical centers in one city, and as such, results may not be generalizable to other institutions. Although the majority of states are restrictive in who is allowed to serve as a patient's surrogate without a legal document, some states, such as Illinois for instance, have very inclusive laws. Looking to states such as Illinois that have successfully included ethically appropriate, but non-traditional surrogates in decision making statutes would help resolve the issues this study highlights.

Although many state laws do not allow non-traditional surrogates to act without a legal document in place, this study did not find any statistically significant differences between traditional and non-traditional surrogate-patient relationship characteristics that should serve to restrict the ability of non-traditional surrogates, such as grandchildren and grandparents to serve as decision makers. The findings of this study suggest that requiring **non-immediate family** members to take the extra step of formal appointment through a legal channel may not be necessary to protect patients. Therefore, broader state laws expanding the list of surrogates authorized by state statute to include more non-traditional surrogates **such as grandparents, grandchildren, nieces, and nephews** may be necessary. While the results of this study suggest that reevaluating state surrogate laws would be beneficial in order to connect legal and ethical mandates, further research and policy debate is important for determining the best way to broaden who may serve as a surrogate decision maker.

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Table 1

Relationship of patient to the acting surrogate.

Surrogate Relationship to Patient	Frequency n (%)
Traditional Surrogates	***n=312 (85.7)***
Spouse	61 (17)
Child	243 (67)
Sibling	9 (2)
Parent	0 (0)
Non-traditional Surrogates	***n=52 (14.3)***
Grandchild	9 (2)
Niece or Nephew	17 (5)
Step-children	5 (1)
*Other Relative	16 (4)
Unmarried Partner	1 (<1)
Friend	3 (<1)

*Other relative includes aunt or uncle, great-niece or nephew, relatives in-law through marriage

Table 2

Patient and Acting Surrogate Relationship Characteristics

	Traditional Surrogate Frequency (%) (n=312)	**Non-Traditional Surrogate Frequency (%) (n=52)**	***p*-value**
Surrogate Age	58.74 (11.08)	55.53 (11.91)	0.0590
Surrogate Education	14.06 (2.62)	13.46 (1.85)	0.0474
Patient sex			0.4417
Female	189 (60.6)	35 (67.3)	
Male	123 (39.4)	17 (32.7)	
Patient race			
African American/Black	80 (25.6)	21 (40.4)	0.1310
White	221 (70.8)	30 (57.7)	
Asian	3 (1.0)	1 (1.9)	
American Indian/Alaskan	1 (0.3)	0	
Multi-racial	7 (2.2)	0	
Hispanic	2 (0.6)	1 (1.9)	0.3711
Refused to answer	0	0	

Table 3

Frequency of surrogate/patient in-person communication

	In-person: Traditional Surrogate Frequency (%)	In-person: Non-Traditional Surrogate Frequency (%)
≥ Weekly	167 (85.2)	29 (85.3)
Monthly	24 (12.2)	5 (14.7)
≤ Once per Year	5 (2.6)	0
Never	0	0
P-Value	0.9023	